



A Three-Way Conversation, VHS, 20 minutes

A video on the effective use of cultural mediators, interpreters, and translators. Comments and insights from both parents and service providers. Produced by the Spectrum Project and Project A.C.T. of the University of Colorado at Boulder, Department of Speech, Language and Hearing.

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Skills to Ease the Journey

Module 2

Partnering with Families as They Guide the Way

Skills to Ease the Journey

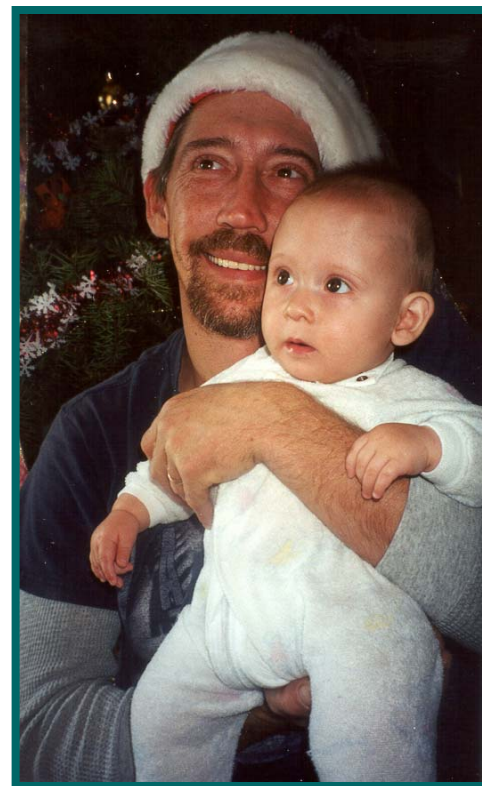


Skills to Ease the Journey

Partnering with families in ways that support their unique culture, values, and language requires knowledge and skill.

Active listening techniques, the use of People First Language, and basic Do's and Don'ts for home-visiting are skills the service coordinator can develop.

These skills are consistent with a family-centered approach which is crucial to fostering a strong relationship upon which a partnership can be built.





Skills to Ease the Journey

Active listening is a way of listening and responding to another person that facilitates a common understanding.

When relationships are strong, communication flows.





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Elements of Active Listening

Do

- Be attentive to the speaker
- Suspend judgment while you listen

Don't

- Compare one situation with another
- Rehearse what you will say next
- Attempt mind-reading

Adapted from Colorado Core Service Coordination Training



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Do

- Reflect back to demonstrate your interest and provide feedback
- Summarize key points to confirm that you understand

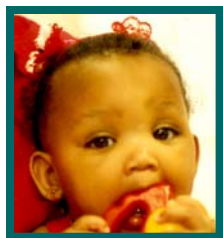
Don't

- Judge
- Attempt to advise
- Divert
- Be concerned about being right
- Placate

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Active Listening Level I

- We listen only to the content of what the speaker is telling us.
- This level of listening tends to elicit personal reactions and "chatter" in our heads, such as judgment or opinions.
- These distractions can prevent us from really listening and understanding what the speaker is communicating.

Adapted from Colorado Core Service Coordination Training



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Active Listening Level II

- We listen for more than the content – we also listen for the speaker's culture, agenda, values, vision, perspectives, and concerns.
- Because we are listening for more, we are more likely to develop a deeper understanding of what the speaker is telling us.

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Active Listening •Level III



- We listen for an even bigger picture.
- We consider all of the influences to the conversation and the environment.
- We are really listening to all our senses, and we pay attention to tone of voice, body language, and environmental factors that are related to the conversation.

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Skills to Ease the Journey

People first language refers to communication practices that treat persons with disabilities with the same dignity and respect afforded to persons without disabilities.

- Focus on the individual, not the disability.
- Avoid labeling people.
- Emphasize abilities rather than limitations.
- Keep a person's disability in perspective.
- Talk about people in ordinary terms.



Adapted from Colorado Core Service Coordination Training



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Examples of People First Language

Say:

People with disabilities.
He has a cognitive disability.
She has autism.
He has Down Syndrome.
She has a learning disability.
He has a physical disability.
She's of short stature/she's a little person.

Instead of:

The handicapped or disabled.
He's mentally retarded.
She's autistic.
He's Down's.
She's learning disabled.
He's a quadriplegic/crippled.
She's a dwarf/midget.

Snow, Kathie. (Rev. 2003). *People First Language*. Woodland Park, CO. [Online]. Available: <http://www.disabilityisnatural.com/pdf/PFL.pdf> [Retrieved: 2004, March 15].



Skills to Ease the Journey

Say:

He has an emotional or mental health disability.

She uses a wheelchair/mobility chair.

He receives special ed services.

Typical kids or kids without disabilities.

Congenital disability.

Instead of:

He's emotionally disturbed.

She's wheelchair bound/confined to a wheelchair.

He's in special ed.

Normal or healthy kids.

Birth defect.

Snow, Kathie. (Rev. 2003). *People First Language*. Woodland Park, CO. [Online]. Available: <http://www.disabilityisnatural.com/pdf/PFL.pdf> [Retrieved: 2004, March 15].



Skills to Ease the Journey

Say:

Brain injury.

Accessible parking, hotel room, etc.

She needs... or she uses...

Instead of:

Brain-damaged.

Handicapped parking, hotel room, etc.

She has a problem with...

And no more “special needs!” That term evokes pity, and a person’s needs aren’t special to him, they’re normal and ordinary! Keep thinking – there are many descriptors we need to change.

Snow, Kathie. (Rev. 2003). *People First Language*. Woodland Park, CO. [Online]. Available: <http://www.disabilityisnatural.com/pdf/PFL.pdf> [Retrieved: 2004, March 15].



Skills to Ease the Journey

“We must always remember that the children we serve belong to their families, and we are privileged to be in their lives for a short time.”



Bruder, M.B. (2000). *“Family-centered early intervention: Clarifying our values for the new millennium.”* Topics in Early Childhood Special Education, 20(2), 105-115, 122.



Skills to Ease the Journey

Do's and Don'ts for Early Intervention Home Visits

- Take a few minutes to think and relax prior to each visit to get yourself off to a good start.
- Go into each home visit as if it is the only thing you have to do all day and there is no place you would rather be.
- **Don't** impose your own values. Support the culture, values, and language of each child's home.



Bard, Rene. (2004) *Do's and Don'ts for Early Intervention Home Visits*. Training Presentation. University of Tennessee at Martin.



Skills to Ease the Journey

Do

- Focus on the family.
 - ❖ If the mother sells Tupperware, ask how sales are going.
 - ❖ If the grandfather has been ill, be sure to ask about him.
 - ❖ If a sibling is involved with sports, ask about a recent game.
- Be genuine.

Don't

- Exclude other members of the family from your visit.



Bard, Rene. (2004) *Do's and Don'ts for Early Intervention Home Visits*. Training Presentation. University of Tennessee at Martin.



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Do

- Find and build on the positive aspects of the family and be a good listener.
 - ❖ Begin the visit with a positive statement about the family or child to let the family know you are paying attention to their efforts and to build rapport.

Don't

- Discuss other families in your program.



Bard, Rene. (2004) *Do's and Don'ts for Early Intervention Home Visits*. Training Presentation. University of Tennessee at Martin.



Skills to Ease the Journey

Do

- Be flexible.
 - ❖ If a family is outside when you arrive, adapt to the situation.
 - ❖ If a family needs to change their appointment time, do everything possible to work it out for them.

Don't

- Be the center of attention.



Bard, Rene. (2004) *Do's and Don'ts for Early Intervention Home Visits*. Training Presentation. University of Tennessee at Martin.



Skills to Ease the Journey

Do

- Be prompt.
 - ❖ Being on time, shows the family their visit is important to you.
 - ❖ If you are going to arrive early or late, call to prepare the family and get their permission for the change.
- Dress appropriately and in a manner that will make families feel comfortable.

Don't

- Expect perfection from the family.



Bard, Rene. (2004) *Do's and Don'ts for Early Intervention Home Visits*. Training Presentation. University of Tennessee at Martin.



Skills to Ease the Journey

Don't

- Remain in an uncomfortable or unsafe situation. Taking care of the service coordinator is important too.

Do

- Present yourself as a professional with confidence.
- Be yourself.
 - ❖ Be genuine in all you say and do. Families value sincerity, and sincerity builds trust.
 - ❖ Develop a good reputation in your community, and you will be able to build relationships with families that promote success.



Bard, Rene. (2004) *Do's and Don'ts for Early Intervention Home Visits*. Training Presentation. University of Tennessee at Martin.



A New Way of Thinking

The Disability is Natural Book and Video -
They're changing lives and attitudes!

About Us

People First Language - It's all about respect and dignity, not political correctness!

The Disability is Natural Store -
Tees, totes, posters, badges, and more to promote positive images!

*To ensure **Inclusion, Freedom, and Respect** for all, we must use*

PEOPL**E** **F**IRST **L**ANGU**A**GE

A commentary by [Kathie Snow](#)

Who are the so-called "handicapped" or "disabled"?

According to stereotypical perceptions, they are:

People who suffer from the tragedy of birth defects.

Paraplegic heroes who struggle to become normal again.

Victims who fight to overcome their challenges.

Categorically, they are called retarded, autistic, blind, deaf, learning disabled, etc., etc., etc.—ad naseum!

Who are they, really?

Moms and Dads. . . Sons and Daughters . . . Employees and Employers
 Friends and Neighbors . . . Students and Teachers. . . Leaders and Followers
 Scientists, Doctors, Actors, Presidents, and More

They are people.

They are people, first.

People with disabilities constitute our nation's largest minority group. It is also the most inclusive and most diverse: both genders, any sexual orientation, and all ages, religions, socioeconomic levels, and ethnicities are represented. Yet people who have been diagnosed with disabilities

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are all different from one another. The only thing they have in common is being on the receiving end of societal misunderstanding, prejudice, and discrimination. Furthermore, this largest minority group is the only one which *any person can become part of, at any time!* Some join at birth--others in the split second of an accident, through illness, or during the aging process. If and when it happens to *you*, will you have more in common with others who have disability diagnoses or with family, friends, and coworkers? How will you want to be described? And how will you want to be treated?

The Power of Language and Labels

Words are powerful. Old and inaccurate descriptors, and the inappropriate *use* of these descriptors, perpetuate negative stereotypes and reinforce an incredibly powerful attitudinal barrier. *And this invisible, but potent, attitudinal barrier is the greatest obstacle facing individuals who have disability diagnoses.* When we describe people by their medical diagnoses, we devalue and disrespect them as individuals. Do you want to be known primarily by your psoriasis, gynecological history, the warts on your behind, or any other condition?

Worse, medical diagnoses are frequently used to define a person's potential and value! In the process, we crush people's hopes and dreams, and relegate them to the margins of society. If we know about (or see) a person's diagnosis, we (mistakenly) think we know *something important* about him, and we give great weight to this information, using it to determine how/where a person will be educated, what type of job he will/won't have, where/how he'll live, and more. In effect, a person's future may be determined by those with authority over him, based on the diagnosis. Today, millions of children and adults with disability diagnoses are effectively "incarcerated" behind the walls of "special (segregated) places": special ed classrooms, congregate living quarters, day programs, sheltered work environments, and more—all because of the diagnosis that's been assigned. *When incorrectly used as a measure of a person's abilities or potential, medical diagnoses can ruin people's lives.*

Inaccurate Descriptors

“Handicapped” is an archaic term—it’s no longer used in any federal legislation—that evokes negative images (pity, fear, and more). The origin of the word is from an Old English bartering game, in which the loser was left with his “hand in his cap” and was thought to be at a disadvantage. A legendary origin of the “H-word” refers to a person with a disability begging with his “cap in his hand.” This antiquated, derogatory term perpetuates the stereotypical perception that people with disability diagnoses make up one homogenous group of pitiful, needy people! Other people who share a certain characteristic are not all alike; similarly, individuals who have disability diagnoses are not alike. In fact, people who have disabilities are more *like* people who don’t have disabilities than different!

The “handicapped” descriptor is often used for parking spaces, hotel rooms, restrooms, etc. But most accommodations so designated provide access for people with physical or mobility needs. These modifications may provide little or no benefit for people with visual, hearing, or cognitive diagnoses. This is just one example of the inaccuracy and misuse of the H-word as a *generic descriptor*. (The accurate term for modified parking spaces, hotel rooms, etc. is “accessible.”) “Disabled” is also not appropriate. Traffic reporters frequently say, “disabled vehicle.” (They once said, “stalled car.”) In that context, “disabled” means “broken down.” *People with disabilities are not broken!*

**The difference between the right word
and the almost right word
is the difference between lightning
and the lightning bug.
*Mark Twain***

If a new toaster doesn’t work, we call it “defective” and return it for a new one! Shall we return babies who have “birth defects”? The more accurate and respectful descriptor is “congenital disability.”

Many parents say, “I have a child with special needs.” This term typically generates *pity*, as demonstrated by the, “Oh, I’m so sorry,” response, a sad look, or a sympathetic pat on the arm. (*Gag!*) A person’s needs aren’t “special” to him—they’re ordinary! *I’ve never met an adult with a disability diagnosis who wants to be called “special.”* Let’s learn from those with real experience,

and stop inflicting this pity-laden descriptor on others.

What is a Disability?

Is there a universally-accepted definition of disability? No! What constitutes a disability depends on who you ask and what services a person receives. First and foremost, a disability label is a medical diagnosis, which becomes a *sociopolitical passport to services or legal status*. Beyond that, the definition is up for grabs! The “disability criteria” for early childhood services is different from vocational-rehabilitation, which is different from special ed, which is different from worker’s compensation, etc. Thus, disability is a *social construct*, created to identify people who may be entitled to specific services or legal protections because of certain characteristics.

Disability is Not the “Problem”

Because society tends to view disability as a “problem,” this seems to be the #1 word used about people with disability diagnoses. People without disabilities, however, don’t spend a lot of time talking about *their* problems. They know this would promote an inaccurate perception of themselves, and it would also be counterproductive to creating a positive image. A person who wears glasses, for example, doesn’t say, “I have a problem seeing.” She says, “I wear [or need] glasses.”

What is routinely called a “problem” actually reflects a *need*. Thus, Susan doesn’t “have a problem walking,” she “needs/uses a wheelchair.” Ryan doesn’t “have behavior problems;” he “needs behavior supports.” Do *you* want to be known by your “problems” or by the multitude of positive characteristics which make you the unique individual you are? When will people *without* disabilities begin speaking about people with disabilities in the respectful way they speak about themselves?

Then there’s the “something wrong” descriptor, as in, “We knew there was something wrong when...” What must it feel like, to a child, to hear his parents repeat this over and over and over again, throughout his childhood? How would *you* feel if those who are supposed to love and support you constantly talked about what’s “wrong” with you? Let’s stop talking this way!

The Real Problems are Attitudinal and Environmental Barriers

A change in attitude can change everything. If educators believed children with disability diagnoses are boys and girls who have the potential to learn, who need the same quality of education as their brothers and sisters, and who have a future in the adult world of work, we wouldn't have millions of children being segregated and undereducated in special ed rooms.

If employers believed adults with disability diagnoses have (or could learn) valuable job skills, we wouldn't have an estimated 75% unemployment rate of people with disabilities! If merchants saw people with disabilities as customers with money to spend, we wouldn't have so many inaccessible stores, theaters, restrooms, and more. If the service system saw people with disabilities as "customers," instead of "clients," "consumers," or "recipients," perhaps it would focus on meeting a person's real needs (like inclusion, friendships, etc.) instead of trying to remediate a person's "problems."

**If thought corrupts language,
language can also corrupt
thought.**

George Orwell

And if individuals with disabilities and family members saw themselves as first-class citizens who can and should be fully included in all areas of life, we might also focus on what's really important (living a Real Life), instead of a Special Life governed by services that often result in social isolation and physical segregation.

A New Paradigm

"Disability is a natural part of the human condition..."

U.S. Developmental Disabilities/Bill of Rights Act

Yes, *disability is natural*, and it can be redefined as a "body part that works differently." A person with spina bifida has legs that work differently, a person with Down syndrome learns differently, and so forth. And when we recognize that the body parts of people *without* disability

diagnoses are also different, we'll know it's the way these differences affect a person and/or her qualifying for services, entitlements, or legal protections which mandates the use of a disability descriptor.

A disability, like gender, ethnicity, and other traits, is simply one of many natural characteristics of being human. One in five Americans is a person with a disability diagnosis! People can no more be defined by their diagnoses than others can be defined by their gender, ethnicity, religion, sexual orientation, or anything else!

Additionally, whether a person has a disability is often a consequence of the environment. Why are many children not diagnosed until they enter public school? Is it because their parents or physicians were ignorant or "in denial"? Or is it because as toddlers, they were in environments that supported their learning styles? But once in public school, if a child's learning style doesn't mesh with an educator's teaching style, we may say he has a "disability." Why do we "blame" the child, label him, and segregate him in "special ed"? Why don't we simply modify the regular ed curriculum (per Special Ed law) to meet his individual needs?

When a person is in a welcoming, accessible environment, with the appropriate supports, accommodations, and tools, does he still have a disability? I think not. *Disability is not a constant state.* The medical diagnosis may be constant, but whether or not the condition represents a "disability" is often more a consequence of the environment than what a person's body or mind can or cannot do.

Using People First Language is Crucial

People First Language puts the person before the disability, and it describes what a person *has*, not who a person *is*.

Are you "myopic" or do you wear glasses?

Are you "cancerous" or do you have cancer?

Are you "freckled" or do you have freckles?

Is a person "handicapped/disabled" or does she have a disability?

If people with disability diagnoses are to be included in all aspects of our communities—in the ordinary, wonderful, and typical activities most people take for granted—and if they’re to be respected and valued, we must use the ordinary, wonderful, typical language used about people who have not yet acquired a disability diagnosis. (If you live long enough, your time is coming!)

Children with disability diagnoses are children, first. The only labels they need are their names! Parents must not talk about their children in the clinical terms used by professionals. The parent of a child who wears glasses (diagnosis: myopia) doesn’t say, “My daughter is myopic,” so why does the parent of a child who has a diagnosis of autism say, “My daughter is autistic.”?

Adults with disability diagnoses are adults, first. The only labels they need are their names! They must not talk about themselves the way professionals talk about them. An adult with a medical diagnosis of cancer doesn’t say, “I’m cancerous,” so why does an adult with a diagnosis of cerebral palsy say, “I’m disabled.”?

The use of disability diagnoses is appropriate only in the service system (at those ubiquitous “I” team meetings) and in medical or legal settings. Medical labels have no place—and they should be irrelevant—within families, among friends, and in the community.

We often use diagnoses to convey information, as when a parent says, “My child has Down syndrome,” hoping others will realize her child needs certain accommodations or supports. But the outcome of sharing the diagnosis can be less than desirable! A diagnosis can scare people, generate pity, and/or set up exclusion (“We can’t handle people like that...”). In these circumstances, *and when it’s appropriate*, we can simply describe the person’s needs in a respectful, dignified manner and *omit the diagnosis*.

Besides, the diagnosis is nobody's business! Have individuals with disabilities given us permission to share their personal information with others? If not, how dare we violate their trust! Do you routinely tell every Tom, Dick, and Harry about the boil on your spouse's behind? (I hope not!) And too many of us talk about people with disability diagnoses in front of them, as if they're not there. We must stop this demeaning practice.

The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.

William James

Attitudes and language changed as a result of the Civil Rights and Women's Movements. The Disability Rights Movement is following in those important footsteps, and similar changes are occurring.

My son, Benjamin, is 18 years old. More important than his diagnosis are his interests, strengths, and dreams. He loves history, burned fish sticks, classic rock, and writing movie reviews, and he's great at mimicking actors and politicians! He's earned two karate belts, taken drama classes, and performed in five children's theater productions. Benj wants to major in journalism and be a movie critic. He has blonde hair, blue eyes, and cerebral palsy. His diagnosis is only one of many characteristics of his whole persona. *He is not his disability.* His potential cannot be predicted by his diagnosis.

When I meet new people, I don't disclose that I'll never be a prima ballerina. I focus on my strengths, not on what I cannot do. Don't you do the same? So when speaking about my son, I don't say, "Benj can't write with a pencil." I say, "Benj writes on a computer." I don't say, "He can't walk." I say, "He uses a power chair." It's a simple matter of perspective. If I want others to know what a great young man he is—*more importantly, if I want him to know what a great young man I think he is*—I must use positive and accurate descriptors that portray him as a whole, real, wonderful person, instead of as a collection of "defects," "problems," or "body parts."

A person's self-image is strongly tied to the words used to describe him. For generations, people with disabilities have been described by negative, stereotypical words which have created harmful, mythical portrayals. We must stop believing (and perpetuating) the myths—*the lies*—of labels. We must believe children and adults who have been diagnosed with conditions we call disabilities are unique individuals with unlimited potential to achieve their dreams, just like all Americans. People First Language isn't about being "politically correct." It is, instead, about good manners and respect (and it was begun by individuals who said, "We are not our disabilities!"). We have the power to create a new paradigm of disability. In doing so, we'll change the lives of children and adults who have disability diagnoses—and we'll also change ourselves and our world.

***Isn't it time to make this change?
If not now, when? If not you, who?
People First Language is right.
Just do it—NOW***

Examples of People First Language

Say:

People with disabilities.
 He has a cognitive disability (diagnosis).
 She has autism (or an autism diagnosis).
 He has a diagnosis of Down syndrome.
 She has a learning disability (diagnosis).
 He has a physical disability (diagnosis).
 She's of short stature/she's a little person.
 He has a mental health diagnosis.
 She uses a wheelchair/mobility chair.
 He receives special ed services.
 She has a developmental delay.
 Kids without disabilities.
 Communicates with her eyes/device/etc.
 Customer
 Congenital disability
 Brain injury
 Accessible parking, hotel room, etc.
 She needs . . . or she uses . . .

Instead of:

The handicapped or disabled.
 He's mentally retarded.
 She's autistic.
 He's Down's.
 She's learning disabled.
 He's a quadriplegic/crippled.
 She's a dwarf/midget.
 He's emotionally disturbed/mentally ill.
 She's confined/wheelchair bound.
 He's in special ed.
 She's developmentally delayed.
 Normal or healthy kids.
 Is non-verbal.
 Client, consumer, recipient, etc.
 Birth defect
 Brain damaged
 Handicapped parking, hotel room, etc.
 She has problems/special needs.

Keep thinking—there are many descriptors we need to change.

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? 2005 Kathie Snow; revised 01/05.

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Our words reflect the way we think, so let's get rid of descriptors like "handicapped, physically disabled, mentally retarded, learning disabled" and other words that focus on the condition instead of the person. People First Language promotes dignity and respect for all!



Field Observation Form

Working with Families, Service Providers, Translators, and Interpreters

1. Describe the reason the family was referred to the early intervention system.
2. Why was a translator/interpreter thought to be needed?
3. Was the interpreter given information about the purpose of the meeting prior to the visit?
4. Describe the setting and purpose of the meeting you observed.
5. List the participants. (List by category, such as parent, grandparent, neighbor, service provider, parent advisor, therapist, service coordinator, translator, etc.)
6. How was the translator/interpreter selected for this family?

Participant's name _____ 2.11

7. Was this the first time the translator/interpreter had assisted this family or were they familiar with the translator?
8. Did the family appear to be comfortable during the visit?
9. Did the family ask questions during the visit and/or offer comments?
10. What problems, if any, were encountered during the visit?
11. Did you feel uncomfortable during any portion of the visit? Explain.
12. Were family-centered practices observable? List examples.
13. Do you have any suggestions for how the visit could have been more successful for all parties?
14. List any concerns you have about working with translators/interpreters and families, and problem-solve solutions with the trainer at your follow-up discussion.